

# *America's Families Care*

*A Report on the Needs of America's Family Caregivers*

*Issued by the*

*U.S. Department of Health and Human Services  
Administration on Aging*

Fall, 2000



# *America's Families Care*

## *Table of Contents*

Introduction .....	Page 1
Voices From the Community .....	Page 2
Voices of Women: Perceptions & Planning for Long Term Care .....	Page 4
Research on Caregiving .....	Page 7
Conclusion.....	Page 10
Endnotes.....	Page 11

# America's Families Care

## Introduction

According to the most recent National Long Term Care Survey, over 7 million people are informal caregivers, i.e. spouses, adult children, and other relatives and friends. These caregivers provide unpaid help to 5.2 million older people with disabilities living in the community with at least one functional limitation in their activities of daily living. If the work of caregivers had to be replaced by paid home care, the cost would be \$45-94 billion per year.

Family caregivers have always been the underpinning of long term care (LTC) for older persons in this country. Among non-institutionalized persons needing assistance with activities of daily living (*ADLs*), *65 percent* depend solely on family and friends and another *30 percent* supplement family care with services from paid providers. Only a little more than *five percent* rely exclusively on paid services.

The degree of caregiver involvement in LTC has remained fairly constant over more than a decade, bearing witness to the remarkable resilience of the American family in taking care of its elders despite increased family mobility, greater numbers of women in the workforce, and other changes in the family structure. The importance of caregiving is underscored by the fact that 50 percent of the elderly with LTC needs but who have no family network are in nursing homes compared to only seven percent of those who have family caregivers.

To address the tremendous needs of family caregivers, President Clinton proposed the enactment of the National Family Caregiver Support Program through the reauthorization of the Older Americans Act. This program will provide critical support needed by families to assist them in maintaining their caregiving role.

## Voices from the Community

Over the past two years, the Administration on Aging held a series of roundtables with caregivers of older persons who have chronic illnesses or disabilities. These roundtables were held in more than 30 cities across the United States, and involved hundreds of caregivers, service providers, policymakers, and community leaders. The purpose of the roundtables was to gain a more complete understanding of the day to day challenges faced by families caring for their older relatives, and to obtain additional insights into the types of services and supports that would respond to the needs of these and other caregivers.

The unanimous, resounding message delivered by hundreds of individuals who are caring for their older loved ones is **families need help**. The Administration on Aging has met many diverse persons in our country who have shared tears, joys and private details of their daily struggles as they talked of the issues that are important to them as caregivers of their parents, their spouses, their neighbors or friends.

Below is the expression of some of their daily challenges in their own words:

**Chicago, Illinois**, older man caring for his wife, “I took a vow when we got married 54-years ago, and I intend to carry it out. My only fear is that I will die from exhaustion before she does, and who will care for her then?”

**San Francisco, California**, from a single baby boomer working daughter: “It has been a challenge going through this alone. To be able to have someone help me.... for just one half hour or one hour to put (mother) in bed, or get her up in the morning...this would be helpful.”

**Portland, Maine**, caregiver of a 79-year old husband with Alzheimer’s disease: “No one else really knows (what it’s like being a caregiver) unless someone is in that situation. My support (group) is a wonderful opportunity for me to realize what is ahead.”

**Lincoln, Nebraska**, caregiver of husband: “Sometimes I need some time (to myself), and it’s harder to get someone to come than it is to stay home.”

**Milwaukee, Wisconsin**, caregiver daughter: “Respite is my number one need. I’ve been caring for Mom for seven years...in that time, I have had one vacation for 3 days.”

**Sarasota, Florida** female caregiver: “All the time, new people are finding out hey will be caregivers. The sooner caregivers get the information they need, the better they will be as caregivers.”

**Cleveland, Ohio**, son taking care of 84-year-old mother. “Taking care of my mother is a 28 hour a day job. I’ve almost reached the end of my rope. I went five years without a vacation or even a day off, there were times I just wanted to walk out the door and never come back.”

**Denver, Colorado**, Hispanic man: “We need to look at ethnic, racial and cultural variations of caregiving. The numbers of Latinos in this country are growing. But stress is stress. It doesn’t really matter what color you are, or what background.”

**Sioux Falls, South Dakota**, adult day care staff member after assuming an 82-year old man who visited their center was looking for help for himself, and then learning he was looking for help for his 103-year-old mother: “Caregiving can happen at any age, and can continue for many years.”

**Lincoln, Nebraska**, a long-distance caregiver for elderly mother in a rural area: “How to access services (in rural areas) and distance is a huge problem.”

**St. Petersburg, Florida**, caregiver wife: “Friends through discomfort, and family through denial, deserted us and we were left alone and lonely. I was angry at the world as I dutifully changed diapers, bathed and dressed the man I once was lover to. How many years to go?”

**Alexandria, Virginia**, Hispanic baby boomer caring for her mother: “At first I thought it wouldn’t be hard to care for Mom — why not, she cared for me? But Mom doesn’t speak English, so it is hard to find people who speak Spanish to help.”

**Philadelphia, Pennsylvania**, Asian-American service provider: “We have clients who have a major language problem, and never use services. Asian families tend to keep everything inside the family. They need our help too.”

**Milwaukee, Wisconsin**, older man concerned about need for caregiver support in the future: “Do the baby boomers think they are not going to age?”

## **Voices of Women: Perceptions and Planning for Long Term Care**

The sentiments of caregivers expressed in the caregiver roundtables were echoed in a news conference held earlier this year to release the findings of focus group research sponsored by the U.S. Administration on Aging, and the National Association of Area Agencies on Aging, the National Association of State Units on Aging. This research, conducted by Mathew Greenwald & Associates, examined how American women are planning for caregiving needs. It addressed the similarities and differences among age and ethnic groups, explored key messages for developing educational efforts on long term care planning targeted at women, minorities and caregivers, and was designed to raise public awareness about long term care and caregiving needs.

The focus groups examined planning for long term care by American women and probed their current attitudes and levels of awareness, as well as the extent to which they have undertaken future planning. The focus groups were comprised of a diverse group of women across racial, generational and income lines. Women were targeted for this research because they constitute 60 percent of the nearly 35 million Americans age 65 or older and 75 percent of all caregivers of older persons. In 2040, for every 100 men age 65 or older there will be 166 women.

The focus group findings represent an important step in building public awareness about the critical issues of long term care and caregiving. The role of the family is a critical component in the long term care decision-making process. Today, nearly seven million Americans are providing physical and emotional assistance to older relatives that makes it possible for them to remain at home.

Many participants who have acted as caregivers noted hardships and problems including stress, frustration, physical and mental strain and feeling burned out or overwhelmed. Some felt they do not have enough time or energy to meet the demands facing them, and that caregiving takes away from their personal lives. The focus groups confirmed that most people are more comfortable receiving services at home or in an assisted living facility, where they can maintain some degree of autonomy and independence, rather than going to a nursing home.

The personal stories of respondents point to the need for public policy to address what will increasingly become a reality for a growing number of Americans. Focus group participants indicated that some of their challenges could be alleviated by the Administration's National Family Caregivers Support Program, which will provide necessary support for seniors and caregivers.

Other key findings of the focus groups:

- < Most women today do not want to “burden” their children with caring for them as they age. At the same time, many are reluctant to engage outsiders to come to their homes to provide care, nor do they wish to go to a nursing home.
- < Many worry that their financial resources will not be sufficient to provide needed care. Middle class people, in particular, worry that they will “fall through the cracks”, with incomes too high to qualify for government assistance and incomes too low to cover the costs of private long-term care.
- < Without information, many older American women will continue to experience stress, frustration, physical and mental strain. They will be caught in family conflicts, unable to plan for themselves; and they will not be able to make use of the supportive help that is available.

In all of the messages that emerged from the focus groups, the common thread is a pressing need for information - information to provide reassurance that the long term care needs of elders will be met, and information that will permit seniors, baby boomers and caregivers of all ages to engage in rational planning and informed decision-making.

Personal expressions from various focus group participants:

**Baltimore, Maryland**, 75-year-old African American woman: “Many elderly people of today, like my husband and me, are independent, active and can make tremendous contributions to their communities. But just as my own mother required in home services and eventually residential care, so will many more of us as times goes on.”

**Coolidge, Arizona**, 78-year-old Native American woman from Pima Reservation: “Our way of life ensures that there is the (support) group to fall back on today, but we also need support for services that will help us keep our way of life in the future and assist our growing numbers of elders.”

**Seattle, Washington**, 84-year-old Asian American woman: “While I haven’t had time to even think about long term care, I would have to say that if the time were to come, I don’t expect my children and grandchildren to take care of me in their homes or provide financial support.”

**Cincinnati, Ohio** Caucasian baby boomer with aging parents and adult children: “Like other baby boomers, my husband and I are faced with having to think about own futures while our parents are still alive and healthy — and that can be quite a challenge.”

**Miami, Florida**, 52-year old Puerto Rican woman with aging parents and teenage daughter: “Everyone needs to look at the possibility of finding yourself in a situation where long term care is needed. We all need to learn about long term care options and explore them so we start feeling more in control our own future. If we have become aware, gathered information and planned ahead, we will know what our alternatives are, and we can make informed decisions for our loved ones and ourselves.”



## Research on Caregiving

The voices from America's caregivers expressed in our roundtables and focus groups are very consistent with findings from major research studies on caregiving.

### America's Caregivers: A Profile

Based on data from the National LTC Survey and other research, the following factors are characteristics of persons who are caregivers for an older person with disabilities:

- C Gender - Almost 75% of primary caregivers are women.
- C Age - Half of all primary caregivers are 65 and older and slightly over one-third are between the ages of 45 and 64.
- C Living arrangements - Over 66% of primary caregivers live in the same household with the older person for whom they provide care.
- C Family position - 40% of caregivers are spouses and 36% are adult children. The prevalence of spousal caregiving is even higher among older persons with moderate to severe disabilities.
- C Minority status - The incidence of caregiving among Asian-Americans, African-Americans, and Hispanic households is higher than in the general population. In addition, the number of minority family members involved in caregiving is higher than those in non-minority families, particularly among adult children.
- C Family size - The likelihood of becoming a caregiver depends on the number of older family members who are potential care recipients and the number of other family members and friends who are available to serve as caregivers.
- C Care recipient level of disability - The degree of a care recipient's functional disability usually directly relates to the need for caregiving, particularly as the severity of disability increases.

## **Change in Caregiver Roles**

Although each caregiver is different, some events occur to many of those caring for older persons which initiate, modify, destabilize, or end their ability to provide care. Some typical “triggering” events are:

- C A health decline of either the caregiver or care recipient that leads to an inability to perform a necessary task, e.g. the caregiver no longer has the strength to lift the care recipient;
- C Onset of the provision of personal care, such as assistance with bathing, dressing, bladder and bowel evacuation, or other aspects of personal hygiene significantly increases the burden on the caregiver and may require the use of paid care;
- C An acute health episode for the care recipient -- such as a broken hip or other debilitating accident, a heart attack, or stroke -- often means hospitalization followed by discharge back to the home placing significant new demands on the caregiver;
- C Termination of the use of a car or public transportation; and
- C Departure or death of the care recipient.

## **Caregiver Support**

Research on caregiving has focused primarily on the consequences of caregiving, e.g. stress, effects on health, costs, etc. New research has enhanced our understanding of the effectiveness of caregiver interventions. For example:

- C A National Institute of Mental Health (NIMH) financed study by New York University Medical School indicates that providing intensive counseling and support for the caregivers of a patient with Alzheimer’s disease can permit the care recipient to remain at home for up to a year before being admitted to a nursing home.
- C A recent National Institute on Aging (NIA) financed study concluded that adult day services can significantly reduce caregiver stress if caregivers secure the services early.

- C Another recent study financed by Agency for Healthcare Research and Quality (AHRQ) found that an intensive caregiver training program increased caregiver effectiveness in solving problems, changed caregiver feelings of competence, and reduced caregiver depression.

### **Costs of Caregiving**

The costs to caregivers in terms of time, physical and emotional stress, and financial burdens can be tremendous. For example, the National LTC Survey and other research have documented that:

- C Each older person with disabilities who lives with others receives an average of almost 30 hours of unpaid caregiving per week. As disability increases, elders receive more care. Those who are at the greatest risk of nursing home placement receive about 60 hours of informal care per week;
- C Caring for an impaired older person often requires physical demands, e.g., heavy lifting and turning, frequent bedding changes, and helping a person use a toilet — tasks which physically strain caregivers, many of whom are older themselves;
- C Bearing the LTC responsibilities for an older relative or friend with disabilities places terrible emotional strains on the caregiver and often results in depression. These strains can lead to restrictions on contacts with friends, neighbors, and other social contacts in the community;
- C Being a caregiver who is experiencing mental or emotional strain is a risk factor for increased mortality among elderly spousal caregivers. A recent study showed that caregivers who provide support to their spouse and report caregiving strain are 63% more likely to die within four years than non-caregivers; and
- C Two-thirds of working caregivers report conflicts between work and caregiving, requiring them to rearrange their work schedules, work fewer than normal hours, and/or take unpaid leaves of absence. Working caregivers also can incur significant losses in terms of career development, salary and retirement income, and out-of-pocket expenses as a result of their caregiving responsibilities.

There also is a growing awareness that caring for older relatives is exacting a high cost to U.S. business in terms of decreased productivity by working caregivers. A recent study by MetLife estimates the loss to US employers to be between \$11.4 to \$29 billion per year. This includes replacement costs for employees who quit work due to caregiving responsibilities, absenteeism and extra time-off, and workday interruptions.

## Conclusion

Every day families are making tremendous sacrifices to provide the care and support needed by their older relatives. Almost always the provision of this care is willingly provided and motivated by love, respect and concern. However, this care is also provided at a significant cost to the caregiver, not only in financial terms but also in increased emotional stress and health risks.

Families need support to both reduce these risks and to sustain them in their ongoing caregiving roles. Research has demonstrated that these two goals can be achieved through caregiver interventions such as:

- C Information to about available services;
- C Assistance to families in arranging support;
- C Family counseling, peer group support and caregiver training;
- C Respite care; and
- C Supplemental community services.

These caregiver supports can now be a reality for families all across America through the reauthorization of the Older Americans Act, and the funding of the National Family Caregiver Support Program.

## Endnotes:

Assistant Secretary for Planning and Evaluation (ASPE) and Administration on Aging (AoA), 1998, *Informal Caregiving: Compassion in Action*, DHHS, Washington, D.C.

Metropolitan Life Insurance Company, 1997, *MetLife Study of Employer Cost of Working Caregivers*, Metlife Mature Market Group, Westport, CN.

Metropolitan Life Insurance Company, National Alliance for Caregiving, Brandeis National Center on Woman and Aging, 1999, *The MetLife Juggling Act Study*, Metlife Mature Market Group, Westport, CN.

Schultz, R., Beach, S.R., 1999, "Caregiving as a Risk Factor for Mortality", *JAMA*, Vol.282: 2215-19.

Mittelman, M. et. al., 1996, *A Family Intervention to Delay Nursing Home Placement of Patients with Alzheimer Disease*, *JAMA*, 276:1725-31.

Stone, Robyn I., *LTC for the Disabled Elderly: Current Policy, Emerging Trends and Implications for the 21<sup>st</sup> Century*, Millbank Memoria Fund "Work in Progress"

Toseland, R.W., McCallion, P., et. al., 1999, *Health Education Groups for Caregivers in an HMO*, (This study was funded by a grant from the Agency for Health Care Policy and Research).

Zarit, Steven, et al., 1998, "Stress Reduction for Family Caregivers: Effects of Adult Day Care Use," *Journal of Gerontology*, Vol. 53B. No. 5. S267-S277.